

# Ostomy

A U S T R A L I A

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## A hearty and healthy Christmas

ACSA National  
Conference Reports



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## A successful conference

In October the Australian Council of Stoma Associations' annual conference was held in Melbourne. I would like to personally thank the organising committee, attending association delegates and observers for making the conference one of the most successful and productive I have attended. There is a detailed report on the conference elsewhere in this issue so I will not dwell on the detail.

Also in this edition is an article by our Administrative Officer, Kylie McGrory, on the history of the creation of the Stoma Appliance Scheme (SAS). While we now have a highly effective scheme, there are still areas where health services for ostomates could be improved.

## Universal access to stomal therapy services

Over the weeks leading up to the 2017 ACSA Conference I and the ACSA Executive met representatives from the stoma industry, the Commonwealth Department of Health, the Department of Human Services, stomal therapists and associations. A common outcome from those discussions has been a recognition that delivering better access to stomal therapy services to improve health and lifestyle outcomes for ostomates will require a collective effort from all stakeholders. There is an emerging concept that improved outcomes that capitalise on the benefits provided by the Stoma Appliance Scheme would best be achieved by forming a stakeholders' forum with membership drawn from:

- The Stoma Industry Group (SIG), which represents the product supply companies;
- the Department of Health;
- the Department of Human Services;
- the Australian Association of Stomal Therapy Nurses (AASTN); and
- ACSA.

The objective of a stakeholders' group would be to identify collaboratively all the issues involved in establishing a method for delivering universal access to stomal therapy services. The next challenge we face is to ensure that those issues are addressed and the service is established. As the development of the SAS demonstrates, improving delivery of health services takes time and concerted lobbying to government. One of the activities necessary to support that lobbying is to identify and quantify the benefits of providing access to stomal therapists and to demonstrate a

cost-benefit for the service. We have substantial anecdotal evidence of the beneficial health and lifestyle outcomes and now we have to establish a methodology to collect detailed data to verify that conclusion.

## Stoma Appliance Management System (SAMS)

Also in this issue is a detailed report on the implementation of SAMS in the WA Ostomy Association. Introducing new technology always provides challenges and WAOA's experience was no exception. However, SAMS offers more than a modern, supported and sustainable way for associations to manage distribution of products available under the SAS. Those associations that are now on SAMS have seen increased efficiency in meeting members' needs through improved utilisation of their team members.

As more associations migrate to SAMS we have the opportunity to analyse depersonalised data on product usage. This information can be used to refine the operation of the SAS and demonstrate to government that the scheme continues to deliver value. I wish to make it very clear that the privacy of individual members will be protected in collecting this information.

## Stoma Appliance Scheme

The scheme operates to ensure ostomates have access to the appliances they need. This places an **obligation on every ostomate to obtain only the supplies that he or she needs, not the maximum quantities available.** A reasonable approach is to order only what is required each month. In the initial stages it is prudent to build up a two-month reserve in case the preferred product is temporarily unavailable. That reserve stock should be turned over so it is always in date. There is absolutely no need for any ostomate to accumulate and hold more than the current month's supply plus a two-month reserve.

In closing, I believe establishing a stoma stakeholder forum would bring together the expertise required to identify and resolve all the issues that need to be addressed to establish a stomal therapy service that is available to all ostomates at any time in their journey through life with a stoma.

**Geoff Rhodes** PRESIDENT



## We want to hear from you!

*Ostomy Australia* is your publication. We are looking for your stories, your experiences, your letters, your photographs.

Ostomates continually tell us how much pleasure—and how much useful information—they get from the journal. But we rely on your contributions.

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- please don't identify medical professionals unless they have agreed to their name being used;
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- photographs should be JPGs and at least 1MB in size. If there are people in the picture, let us know that they agree to publication.

Send your contribution to:  
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## New inquiry into future ACSA structure

The Australian Council of Stoma Associations will carry out a more detailed assessment of the legal structure under which it operates, as part of the continuing debate about the future character of the national body.

The decision was made after an extended debate at the 2017 national conference in Melbourne in late October, arising from delegates' consideration of a report on the deliberations of the ACSA Structure Working Party.

That working party was set up by a decision at the 2016 conference, and was charged with identifying an alternative organisational structure for Australian ostomy that would provide it with a platform to strike a formal contract with the Australian Government. The working party was asked to recommend a structure that retained the services of the 22 ACSA member associations but which would allow ACSA to meet government requirements for a formal contractual base.

Debate at conference revolved around the question of whether ACSA should remain an incorporated association or change to become a company limited by guarantee. The latter is a form of

public company designed for non-profit organisations, subject to the Commonwealth Corporations Act 2001.

In the working party minutes presented to conference, party chair Janice Anderson noted that little progress had been made in drafting advice to associations because updated Stoma Appliance Scheme guidelines recognised ACSA as the organisation responsible for monitoring associations' compliance with the guidelines.

'As one of the key reasons for reviewing the structure of ACSA was to identify a structure with which the Department of Health would be comfortable in entering into a contractual arrangement, and thereby giving ACSA the ability to monitor associations' compliance with the guidelines on behalf of the Department, the urgency to change structure has diminished,' she said.

Nonetheless, it was recognised that 'it is still necessary to explore alternative structures to ensure that the structure of the national organisation is as effective as it can be, particularly with respect to our future activities'.

In the conference discussion, opinion

was divided on whether the existing incorporated association structure provided the necessary safeguards against liabilities. Several speakers maintained that moving to become a company limited by guarantee was unnecessary, and one participant claimed that a company structure would allow government officials to stymie ACSA by insisting that, as 'shareholders', all associations would have to agree to an initiative.

The national president, Geoff Rhodes, told the conference that we were not talking about changing the structure of individual associations, but the structure of ACSA. One advantage of a company limited by guarantee was that it would be able to operate nationwide, rather than being constrained by the laws of the territory where it is registered. In either case the voting strength of the separate associations would be maintained. He urged delegates to authorise a proposal for change to be prepared.

Stephen Grange (Ostomy NSW) agreed that options for change should be examined, but insisted that delegates needed a more detailed document to consider.

*Continued page 6*

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Members of the ACSA Executive at the 2017 national conference in Melbourne – from left, Administrative Officer Kylie McGrory, President Geoff Rhodes, Vice-president David Munro and Treasurer Robert Barsing.

Subsequently, a majority agreed that 'a detailed report into adopting a company limited by guarantee structure for the national organisation, in lieu of an incorporated association, be prepared for consideration at a meeting to be held in conjunction with the 2018 meetings'. The report is to cover both the legal and financial ramifications of such a change, and will go to national conference in Sydney next year.

**Conference** also decided to set up a working party to look at developing formal contractual arrangements between ACSA and its component associations on the one hand, and supplier companies on the other. That would include firm service delivery agreements.

Some delegates said there seemed to be no service-level agreements or contracts with the companies, despite the fact that associations were involved in a scheme with outlays of more than \$90 million a year.

Geoff Rhodes confirmed that supplier companies' contracts were with the Department of Health. He argued that ACSA's aim should be to move to a situation where ostomate organisations set contract conditions and terms of trade. A motion to investigate the question was passed by a majority.

**ACSA** will renew its request to the Department of Health that it consider allowing dual ostomate status for people with a complex or long-term fistula in addition to a primary stoma.

Lorrie Gray (WA Ostomy Association) drew attention to the impact of the Health ruling that a fistula could not be treated as a second stoma but that supplies to manage the condition subsequent to a primary stoma had to be accompanied by an application for additional stoma supplies.

Conference was told that the department set the parameters for the Stoma Appliance Scheme. Past president Gerry Barry said similar requests had been made to the department in the past, but without success. The department had argued that changes must not expand the ambit of the scheme.

Sue Hoyle (Ostomy Tasmania) believed that this was 'a management issue' because associations were not looking to expand the scheme but to restore a dual entitlement authority that had been changed a few years before. Thus a request for leniency faced an administrative rather than a financial barrier, as it was unlikely to have an impact on total scheme expenditure.

**The Australia Fund** had supported ostomates in several overseas countries during 2016-17, the fund delegate, Gerry Barry, told conference.

The fund had supported three locations in Indonesia, three in The Philippines, and locations in Papua New Guinea, Fiji, Malaysia, Mongolia, East Timor and Kenya. It had received strong support from the most involved association coordinators at Ostomy of South Australia, Gold Coast Ostomy, Queensland Stoma and Queensland Ostomy, ACT and Districts, Ileostomy Association of South Australia, Stoma NSW and WA Ostomy.

National management of the fund had been constrained by the inability to recruit either an administrative coordinator or a national relief coordinator, though this had improved recently with an appointment to a new position combining both responsibilities.

In summary, Gerry said, 'we have been able to respond to most requests received from our overseas coordinators, although we have to accept that some of the larger overseas associations, with over 100 members, are really only partly supported because the quantities needed for full support are beyond our financial and physical capacity.' ●



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1. Nichols, T. Hannestad, V. and Purnell, P. Supporting stoma hygiene: a cross-sectional survey on the use of Dansac skin lotion tissue (wipes) - Australia, Supplement to the WCET Journal, 2014 April-June Volume 34, Number 2. \* R2 restriction, no authority for an increase in the yearly allocation can be granted.

# Support? Sign in with social media

Ostomates have always understood the advantages of sharing knowledge and information, and supporting their fellows. To personal contact and traditional tools, **Erin Goodwin** explains, social media has added a new, dynamic dimension.

Let me just say wow! Thank you, social media. How times have changed. Going back ten years, when my journey began, social media may have existed but not in the glorious form it does these days. The ability to connect to others across barriers is astounding. I am so blown away by the magnitude of support groups, pages, blogs and websites that are out there. The time and effort that members of the ostomy community put into supporting each other is astronomical. One of my main drivers for setting up InsideOut Ostomy Life earlier this year was to ensure that other ostomates knew not only that there was support out there but where to find it.

As part of that, I wanted to collate some of the amazing resources out there. So I simply searched the words 'stoma', 'ostomy', and 'ostomate' in Facebook and filtered on groups and then pages. I was overwhelmed by the sheer number I found and wondered why I hadn't done this earlier. Within the multitude of Facebook groups I found some small, some large. Some allow pictures in feeds, others only in comments. Some are out and proud while others are a little more reserved. All of them are supportive, non-judgemental, accepting and knowledgeable in the ways of ostomy life. So no matter where you are at in your ostomy journey, if you are computer literate then there is support out there for you.

If you are not then I suggest getting a family member to help you get connected, because once connected you will wonder why you also didn't do this earlier. One tip I would give you, especially if you are new to social media, is to turn off your notifications so you don't get

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## 'Sharing your story has a power to help others'

For Erin Goodwin, the best thing about flying to the United States to receive her WEGO Health Award wasn't the hype around the presentation ceremony in Arlington, Virginia, or even being handed the award sculpture. It was 'meeting and connecting with the other winners and the WEGO Health team'.

'They are all doing wonderful things in their fields, and they inspire me to continue with the journey I have begun,' she says. The 'wonderful things' that Erin has been doing on social media saw the Perth resident, president of the WA Ostomy Association, named Rookie of the Year in the international awards that are conferred by WEGO Health, a Boston-based company which aims to improve healthcare by connecting the experience, skills and knowledge of 'patient leaders' with medical companies and professionals. Erin's accolade at the Fifth Annual Patient Advocacy Summit came for her work in setting up and running InsideOut Ostomy, the blog and social media presence that she set up in April 2017 and 'which focuses on living a full,

active, healthy life with an ostomy bag'.

Erin's own journey began a decade ago, when she was diagnosed with ulcerative colitis. After becoming an ostomate she was involved for several years with support groups, advocacy and local activities, and in 2016 won Convatec's Great Comebacks Award. 'But I was never brave enough to step out to a global kind of thing until this year,' she says. 'And since then it's been huge.'

Erin says those who become patient advocates have been through, or are still going through, some kind of chronic illness or health problem—and they've just decided, like me, that sharing your story has a power to help other people. They've put themselves out there to be helpful, and to aid other people'.

The awards recognize that what health care recipients can tell pharmaceuticals and medical professionals is especially valuable. When you're in the midst of the serious part of your illness, it's hard to get out of your bubble, Erin says. Only later can you look back clearly and

figure out what you've learnt. 'If medical professionals and pharmaceutical companies are willing to listen, that's fantastic, because it can only help other people in the future.'

As a member of WEGO's patient expert group, Erin will be plugged into the medical network worldwide. 'As a member of the patient expert group, my profile will accessible to pharmaceutical companies and/or medical professionals for studies, input and/or speaking engagements that relate around any of the things that I've dealt with or I deal with on a daily basis.'

All that, on top of maintaining InsideOut Ostomy and chairing WAOA? How much time does that leave? 'If I could figure a way to be able to cover my daily living costs, then I would be quite content to have it take over my life, because this is where I feel passion,' Erin says. 'I feel comfortable when I'm doing that. It's kind of selfish in its own way—I know I'm helping other people, but it helps me as well. I think everyone that helps others feels that.'



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overwhelmed with the constant ping of new posts and comments, as the online world is alive 24 hours a day and does not sleep, because it covers all time zones.

I also propose taking some time to check out the variety available and picking the pages/groups that fit you best, as each one highlights different aspects of ostomy life. Many of the Facebook groups, if not all, are closed groups and you will need to ask permission to join. The benefit of closed groups is that anything you post will only show in the feeds of the members of that group, so if you're not at the public bags-out sharing stage with non-ostomates, then there are no concerns, as it's private—well, as private as social media can be.

As the Facebook online support options are immense, to save you time searching I have added a resources section to my webpage InsideOut Ostomy Life that has 50 of the top Facebook groups and top 20 pages that showed in my feed with 100-plus members/likes complete with short descriptions I found online. Many descriptions are only snippets, with full descriptions and more information available through the links connected to the group/page name. Please note: While all these groups are fantastic, and there is a wealth of knowledge shared by ostomates, it's your responsibility to have any and all advice offered to you checked with your medical practitioner and/or stomal therapy nurse before acting upon it.

If you are not a Facebook fan, Instagram is another fantastic social media outlet. Search using #s (hashtags) with key words to find people to follow who align with your interests and values. By searching a few key words, it was astonishing, the host of amazing advocates I found whose photography showed ostomy life and the amazing things we are capable of.

Not a social media fan at all? Google is your friend. Many advocates who have social media accounts have associated websites or blogs, which can be a great source of information and comfort. One of the best for all things ostomy that I have come across, and the recent winner of WEGO Health's Best in Show: Blog Award is Eric from Vegan Ostomy—and of course please take the time to check out InsideOut Ostomy Life, my blog, which is a work in progress that recently won WEGO Health's Rookie of the Year Award.

While online support is amazing and can get you through many lonely nights, if you are like me it's nothing like meeting up and having a chat over a good coffee or hot chocolate with some like-minded people travelling the same path as you. So if you have a local



Erin Goodwin with Jack Barrette, CEO and founder of WEGO Health, after receiving her Rookie of the Year Award in Arlington, Virginia, in October 2017.

support group in your area, I would strongly recommend going along and meeting some other ostomates face to face. It's amazing how seeing and talking with another ostomate can make you feel less alone and isolated in an instant.

If you don't have a support group in your area, why not set one up? That's exactly what I did. Social media is an excellent way of finding locals and engaging with them before meeting up. Some groups are set up for specific regions, so if you're looking for locals you need to find those groups. When I went looking for support groups in my area and found none I used my contacts through the association in my state to start one, and then used social media to expand it.

If you don't have access to an association there are plenty of not-for-profit companies out there that have meeting spaces available if you ask. This can save the angst of talking about private matters in public places. All you need is two people with a common issue to start something that can grow into a dynamic support group. After 24 months of running support groups, these groups have grown from a handful of regulars to a diverse crowd of ostomates with regular guest speakers and product representatives in attendance.

**Social media handles & webpage/blog details:**

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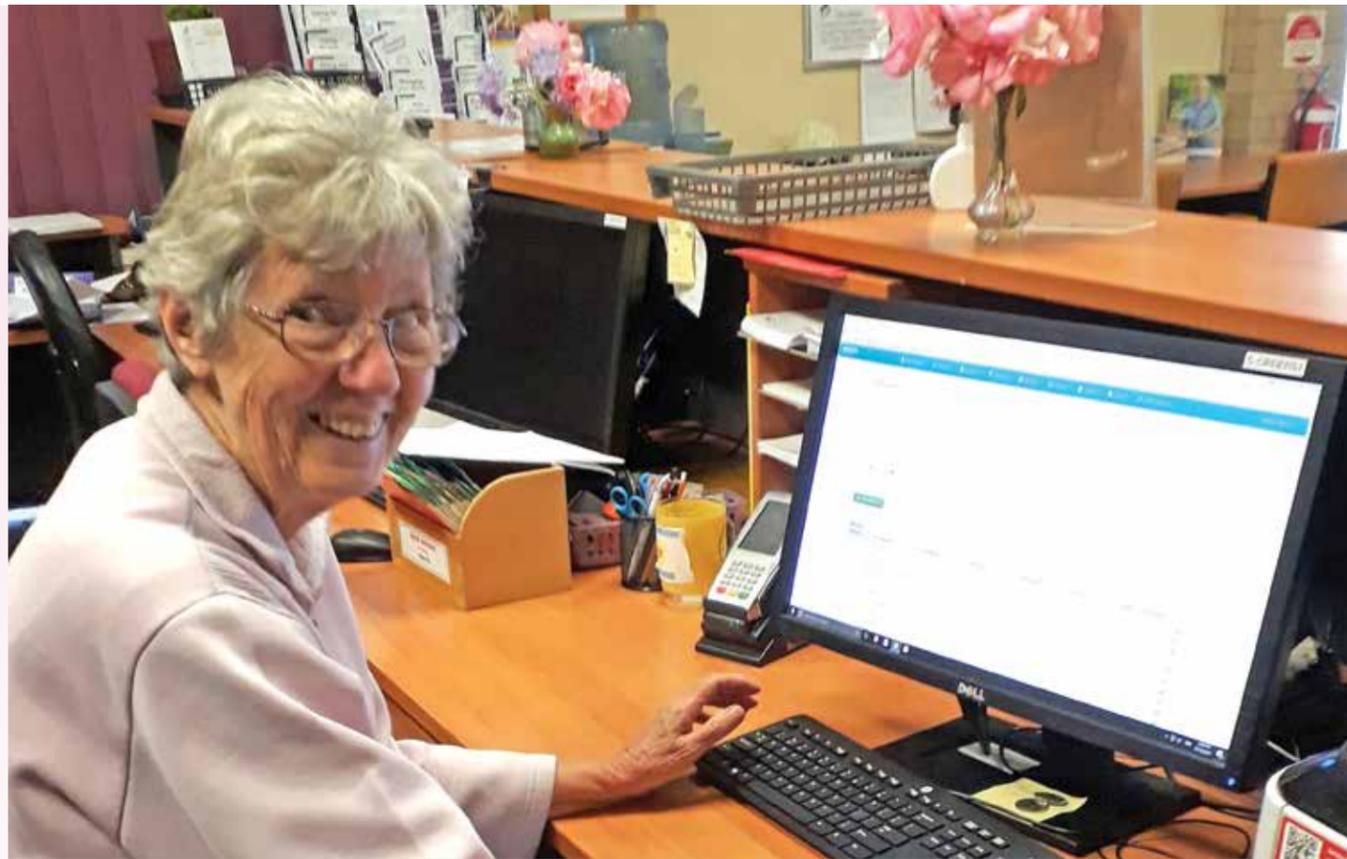
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WA Ostomy Association secretary Lorrie Gray at the keyboard. Introducing any new computer system is time-consuming and sometimes risky.

## Learning from the SAMS problems

*Over the next 12 months associations around Australia will move to using SAMS, the Stoma Appliance Management System developed by ACSA. For most, implementation is expected to be relatively trouble-free—but even when trouble occurs, putting effort into preparation, processes and people can ease the pain. **Natasha Rogers**, General Manager for Western Australian Ostomy Association, tells how her organisation tackled the problems.*

When I joined WAOA in December 2016 as the association's inaugural general manager, I knew that one of my first tasks would be to manage the implementation of SAMS. The association's management committee was strongly committed to introducing the new software system that ACSA had started to roll out around Australia.

But the change immediately prompted a number of questions, especially since the Ostomy program we used was working well and had been trouble-free since it was installed in 2008—a great record for any

software. What benefits would SAMS bring, and would the ability to link to a national system warrant the disruption and costs involved? At the personal level, how would our volunteers, almost 70 all, handle the change? Did WAOA have the organisational capacity and processes to cope with so large a shift?

The answers were compelling, in part because WAOA was facing a number of related challenges. The Ostomy package, though serviceable, was tiring, and would need to be substantially upgraded. Moreover, WAOA needed to overhaul its internal operating procedures, which meant in turn that we would need to upgrade our computer hardware, from a 32-bit operating system to the more advanced and capable 64-bit system. Difficulties had begun to emerge in fulfilling orders from members, more of whom were expecting online access and a higher level of automated responses. These things were loading more pressure on volunteers, whose welfare was a key consideration for WAOA management.

The association accepted ACSA's argument that the environment in which associations were operating was changing. SAMS not only promised to simplify the lodgement of claims and save time and money,

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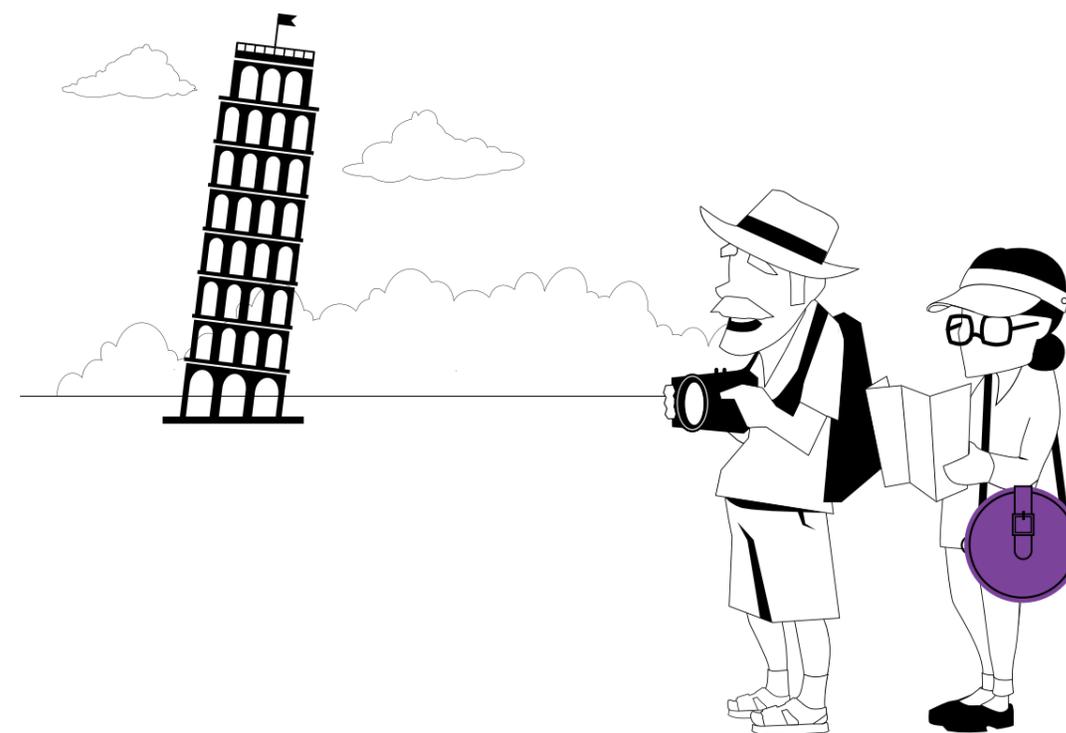
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but also help to draw together data that would give the national body information to use in support of national objectives.

At the association level, SAMS had the potential to improve WAOA's operations, making the tracking and processing of orders more efficient, improving inventory control and management, facilitating management of member records, orders and payments, and providing an opportunity to adopt a just-in-time system that would make ordering more precise while reducing stock on hand. One important additional benefit would be reducing the workload and stress on volunteers.

But we knew that change would not be straightforward. For a start, it involved an outlay of more than \$50,000 to carry out a system-wide technology upgrade. It would also involve restructuring procedures across the association. We worried how our volunteers would react to change of this scale. All our key positions were filled by volunteers, who were used to a mostly paper-based system. Around 40 per cent had no experience with computers. And we expected them to pick up a sophisticated system like SAMS? No wonder we were concerned how they might respond.

In the event, our volunteers' response has been inspirational. They have made an enormous effort to acquire the new skills they need, and they are dedicated to making the system work. One 82-year-old declared that she was determined to learn the system. She made a list of what she wanted to master, and for two months she spent two hours every Monday working her way through the list. But change is hard work, and we also found that it is important to keep people engaged and motivated throughout the transformation.

What problems did we strike along the way? Even though WAOA's situation was probably unique, there are important lessons for other associations.

The need to move from a 32-bit to a 64-bit system was the main technical difficulty. Having dual servers was a huge problem. When we swapped to the new system, we found that we could not use the old software. There were delays and transition issues in getting the new hardware and SAMS to an operational state—but we had no alternative other than to press ahead.

As an aside, when we needed to seek advice and guidance, the 'tyranny of distance' put unexpected pressure on the management team at WAOA. I found myself working across three time zones—the east coast, where Ostomy Association of Melbourne and Ostomy NSW had SAMS running; Adelaide, where Ian Draper was working on data migration, and our office in Perth. For me, this often meant an extended working day that began at 5.30am and ended at 8 o'clock at night. Although other associations won't face the same time-zone problem, they should recognise that getting

SAMS up and running might sometimes mean more than an eight-hour day.

Training was another hurdle. Ideally, the coordination team should have had the kind of detailed functional documentation that would have allowed us to cross-check requirements and set up a training schedule for volunteers, and have training manuals for those who would be using the system. It would have been advantageous, too, in spending time seeing the system at work before we went 'live', but in the circumstances, that wasn't possible. Because we had to use dual servers during the transition, opportunities to expose staff to working SAMS system were limited.

However, we believed it was important to see SAMS in operation, and the site visit WAOA staff made to OAM in July was a crucial turning point: seeing that efficient operation first-hand gave us important insight into the operating capabilities of SAMS.

The transition is a work in progress, but things are improving. We have a splendid new updated computer system but it will take some time to improve workflow and operational processes so that our 3800 members get its full benefit. We are working to close some of the skills gaps that change exposed—we have lots of volunteers but work is continuing to match skills and abilities with requirements. There were also compatibility issues in migrating data from Ostomy to SAMS, as not all the fields were matched across the platforms. Some of these issues are still being resolved.

WAOA has learned much from the changeover. We recommend that, as other associations prepare to adopt SAMS, you talk to as many people as possible about their processes, and compare them with your own. You should get the software ahead of time and 'play' with it as much as possible before going live. Take stock of your operational processes and consider how they might need to change before implementation. Be prepared to invest in IT human resources to support your volunteers. And call on the expertise available through associations that have already made the change.

ACSA has also learnt from our experience. It has understood the need for smooth transitions, and is creating a software environment in Melbourne which will be able to verify data before it is migrated. It is also developing a full set of training documents.

Introducing any new computer system is time-consuming and sometimes risky. Bring a strong transition team together, be prepared to adjust your procedures, spend time on preparation, and make sure that you have expertise on call. A significant amount of transformation work still needs to be done, but WAOA survived the implementation and our members are beginning to get the benefits. I hope our experience helps you, when your time comes. ●



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# A hearty and healthy Christmas

**Nutritionist Margaret Allan has some advice to help ostomates make the most of the festive season.**



Christmas can be a wonderful time, with lots of fun, festivities and joy. It can be an opportunity to spend time with family, catch up with friends you haven't seen for a while, and enjoy all the special activities on offer at this time of the year.

Christmas can also be a hectic time, with added pressure and stress that can be both physical and mental. It may be a period

when you are engaging in more social outings than usual, consuming foods that are not part of your 'normal' diet, and you are out of your habitual routine. As an ostomate, it is therefore important that you are aware of the extra demands and needs of your body during this time, and take extra care to look after yourself so that you can avoid potential pitfalls and fully enjoy all the special opportunities that are available.

## Physical considerations

Many people have stomal surgery and return to full health and capability, which is a blessing. Others, however, may have ongoing issues that result in lower energy levels and a reduced capacity to cope with normal daily activities. The increased number of social invitations and tasks to attend to during the lead-up to Christmas can create added physical pressure that can be taxing for someone who functions at a sub-optimal level on a normal day. It is therefore important to manage these commitments so as not to create too much added physical strain.

Christmas shopping can be enjoyable or daunting, depending on individual circumstances. Car parking can be an issue, so there may be a need to walk longer distances than usual to reach the shops, and there may be a need to visit a number of retail outlets to purchase all the desired items. Shopping centres can be dry, distracting environments in which you can forget your physical state and that you haven't eaten or drunk anything for hours. Long spells of Christmas shopping can lead to dehydration and exhaustion, so schedule rest stops and breaks while buying your gifts, and make sure you have adequate snacks and drinks to keep you fuelled up and hydrated. You may be surprised at how much more easily you cope with the hustle and bustle of Christmas shopping when you are adequately rested and refreshed with food and fluid. Online shopping can also be a viable alternative to

consider if your physical capacity is limited, because it is much less debilitating.

Social opportunities can quickly fill up the diary at Christmas time, but be mindful of not overcommitting yourself, as this can make social outings taxing and unpleasant rather than festive and enjoyable. There will be some gatherings that you will have no control over, but for others that you are arranging with friends and family, make an effort to spread them out so that you are as refreshed as possible for each occasion. If the weeks leading up to Christmas are becoming too frantic and you feel you cannot manage another outing, then suggest catching up after all the festivities are over, when you will have more time and energy. Keeping to your normal routine and getting a good night's sleep as often as possible can be very beneficial and help you cope with the stress of all the extra activity.

## Christmas cheer

Christmas falls during summer, when heat can create its own challenges for ostomates. I have previously written about the importance of hydration for ostomates, especially during warmer weather, and this issue can be compounded when combined with lots of Christmas cheer.

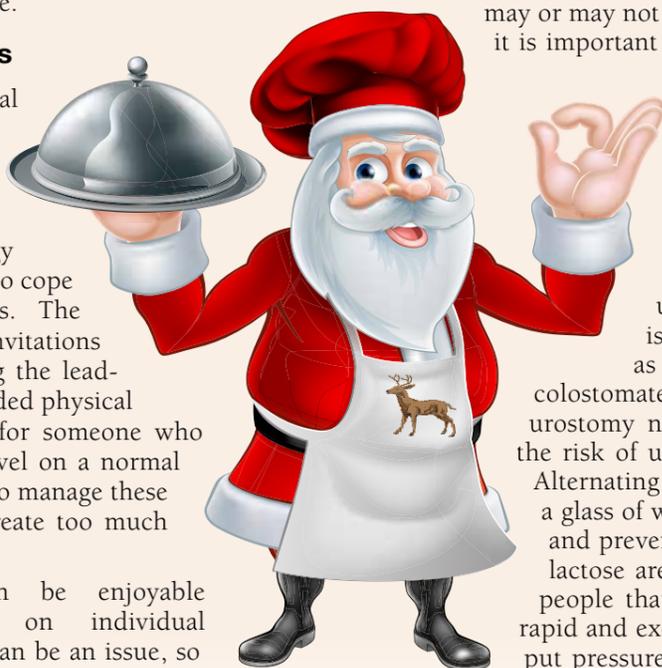
Festive occasions that occur around Christmas may or may not involve alcohol, but if they do it is important to remember that alcohol is a

potent diuretic and as such can be dehydrating. Fluid is lost from the body with each alcoholic beverage and therefore must be replaced frequently and adequately with water or other hydrating fluids to reduce the risk of unwelcome consequences. This is important for urostomates as well as ileostomates and colostomates, because those with a urostomy need adequate fluid to reduce the risk of urinary tract infections (UTIs). Alternating each alcoholic beverage with a glass of water can help to replace fluids and prevent dehydration. Fat, fibre and lactose are common problems for some people that result in diarrhoea, and the rapid and excessive output that ensues can put pressure on the appliance that results in leakage. This situation is compounded if the appliance is not fitting correctly in the first place. Examining dietary intake over a period of time and correlating it with the timing and frequency of accidents can shed light on whether any of these foods are the problem.

if the appliance is not fitting correctly in the first place. Examining dietary intake over a period of time and correlating it with the timing and frequency of accidents can shed light on whether any of these foods are the problem.

## Festive food

There is an amazing array of tasty, enticing food on offer at Christmas time. While it is an opportunity to indulge in delectable treats that are not on offer at other times of the year, some issues with festive food that are important to consider. Many Christmas treats contain nuts, dried fruit and coconut. While the combination of these foods



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Australian ostomates are fortunate to have access to one of the most generous stoma appliance schemes in the world. In 2017 about 3,500 individual items across 11 product groups have been fully subsidised and available to ostomates through the Australian Stoma Appliance Scheme (SAS).

This is a far cry from the situation 50 years ago, when Australian ostomates had to purchase their own appliances and government support was virtually non-existent. To appreciate just how lucky we are to enjoy the wonderful support that the Commonwealth Government provides today, we need to understand the origins of the SAS and the tireless lobbying carried out by the pioneers of our associations to ensure that ostomates can enjoy a vastly improved quality of life.

The foundations of the scheme were laid in the late 1950s and early 1960s. Australian stoma associations had been persistent in lobbying the Commonwealth Government for subsidised ostomy appliances for many years until, in 1960, a petition was sent to the then Minister for Health, Dr Donald Cameron, by the Ileostomy Association of NSW (now Ostomy NSW Ltd) asking that appliances be made available free of charge to Australian ostomates. The petition enjoyed some success and in 1962 a small number of subsidised pharmaceutical agents, such as karaya powder, surgical cement and some silicon cream preparations, became available to ostomates through the Pharmaceutical Benefits Scheme.

Originally these preparations were dispensed by pharmacies upon presentation of a prescription, but amendments to Section 100 of the National Health Act (1953) in 1962 meant that stoma associations could begin to supply the preparations directly to member ostomates. This arrangement established the precedent for the supply of government-subsidised ostomy appliances through stoma associations.

However, the subsidy for ostomy products covered pharmaceutical preparations only. Pouches still had to be purchased, so lobbying by

the indefatigable stoma associations continued. By the late 1960s the issue appears to have drawn quite a bit of interest within the political arena. Successive Opposition leaders, including Gough Whitlam, recognised the electoral potential of promising to subsidise ostomy pouches. However, it was not until 1970 that real progress was made and the tax deductibility of appliances purchased for stoma management was announced in the federal Budget.

Despite this achievement, the associations continued intense lobbying of the Commonwealth Government in pursuit of their goal to have all ostomy appliances completely subsidised. They were supported by the Australian and New Zealand Council of Stoma Associations (ANZCSA) and the Australian Association of Stomal Therapy Nurses (AASTN). In March 1973 the Whitlam Government established a working party to provide the Minister for Health with information on providing medical and surgical aids and appliances, including ostomy appliances.

In April 1974 the working party recommended that the Commonwealth provide subsidised ostomy appliances to all people who needed them, and on Tuesday, 17 September 1974, Federal Treasurer Frank Crean announced that:

*"...it is intended to introduce legislation in 1974-75 to authorise the supply, without charge, of stoma appliances to all persons in the community who need them".*

Finally, on 1 October 1975, the Australian Stoma Appliance Scheme that we enjoy today was born!

*In the April issue: How the evolution of the Stoma Appliance Scheme has influenced the development of stoma associations.*

**A hearty and healthy Christmas** *Continued from page 18*

tastes great, it may lead to an increased risk of a blockage for ileostomates and colostomates, especially if eaten all together and in large quantities. If you choose to indulge in these treats, my advice is to eat only a small amount and chew the food really well. Drinking adequate fluids also helps to reduce the level of risk.

There can be a tendency to consume a lot more sugary foods than normal at Christmas, which for many ostomates may lead to unwanted weight gain. Increased sugar intake may also create an additional risk of urinary tract infections in urostomates with diabetic complications, in particular. Christmas without sweet treats can be rather miserable, so my advice is to eat any sweet foods slowly and savour the taste so you are happy with a small quantity and don't feel that you are missing out.

Many Christmas foods also contain a higher level of fat, and this may also cause concern for some ostomates. The crackling on roast pork and the sauce on plum pudding, for example, may lead to higher output for ileostomates and colostomates, especially if they are eaten in large quantities and fat malabsorption or lactose intolerance are issues. Keeping portion sizes moderate can help to reduce potential problems.

There is no doubt that Christmas can be a time of great joy and happiness. It can also be a time of frantic activity and extra challenges. Make every effort to look after your health during this special time so you can enjoy all the wonderful opportunities. Maintain your routine as much as possible, keep yourself hydrated, reduce portion sizes to avoid potential complications, and focus on the fun and fellowship around you. And then when the New Year comes around, take some time to give yourself the gift of rest and relaxation to allow you to recuperate and regain your energy. You can then start the New Year in the best possible health.

Wishing you a wonderful Christmas and a healthy and happy New Year!

**Margaret**

*Margaret Allan is a nutritionist who advises both ostomates and the general public on diet and health-related matters. She is the director of the consultancy Nutrition for Ostomates. To read more nutrition articles about ostomate health, go to [www.nutritionforostomates.com.au/articles](http://www.nutritionforostomates.com.au/articles).*

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**Dear Editor,**

The August *Ostomy Australia* reported on a seminar speaker who (perhaps mistakenly) spoke of 'stigma', and suggested there were attitudes such as 'public stigma', 'self stigma', 'low self esteem', 'an opportunity for comedy', and 'denigration by celebrities and other public figures'.

In all my years with a stoma I am not aware of ever encountering any of these suggested matters, and I am wondering if other ostomates might have read that article and been left with some wrong feelings concerning the attitudes of others.

May I give a positive and true example? I stood with my wife and two other couples at a function when we were joined by a fourth couple we knew. I said to my friend, 'Hello Frank, I believe you have not been well?' Frank answered 'I'm fine now, and look at what I have got.' Frank lifted up his shirt to show us all a colostomy bag. So I said 'So what? I have one of those.' And I lifted up my shirt and displayed mine.

And the reaction? No embarrassment at all. One wife simply said 'Will you boys stop showing off?' There was no further comment and normal conversation was resumed.

So the message is? Don't feel there is something secretive or shameful about having a bag. Other people are not really interested and probably don't even 'give a hoot'.

**Graeme Owens, WA**

**Dear Editor,**

As a 72-year-old quadriplegic, I had an ileostomy only in December 2015. At that time, like everyone, I not only had support and advice on the range of products available, but also tried many of them to determine what might work for me and what would be my ongoing choice of products to manage the stoma.

I eventually chose to use a one-piece collection bag, a mouldable ring and elastic tapes to secure my device to my skin. To change my device, I used adhesive remover spray and adhesive remover wipes to clean the skin before placing a new bag and helping to secure it with the elastic tapes. I also needed putty to fix uneven skin around my naval.

However, I believe that my change process was flawed. I suspected excess adhesive remover spray was the problem. Not only was it clear, but it seemed difficult to neutralise even with multiple cleans with water, so that I had difficulty

totally removing any residual spray. Remover wipe usage did not appear to have the same effect on glue adherence. This appears to be the case, as I don't have leakages any more when only using the wipes.

Like many others, leakages had been a constant problem and there were days where a morning bag change was closely followed by several leakages requiring more bag changes and wasting good equipment.

In an attempt to prevent leakages and the angst they caused, I trialled not using the adhesive remover spray. By not using it, I was concerned that constantly pulling the device from my skin at each three-day change might cause damage to my skin. However, having now used this new routine change for several months, there have been no skin problems or irritation and certainly no leakages.

In addition to no longer using the spray, I also change my bag just before going to bed at night. This lack of movement also seems to have helped me with bag adherence. This new routine, without the spray and making a night-time bag change, appears to have helped me and I believe may be an approach that others might like to try if leaks are an issue for them.

**Ian Trehwella, ACT**

**Dear Editor,**

I have read people's complaints concerning the Velcro-type seals on their colostomy bags. I too have had an issue in the past and have come up with the simple solution of closing the opening with a foldback clip, of the kind used in offices. I can't feel it and to my knowledge it isn't visible through my clothing.

**Lyn Brayshaw, NSW**

**Dear Editor,**

Linda Nannestad's letter (*Ostomy Australia* April 2017) was interesting and of use to some other ostomates with a bag placed in a similar position. For bags that ride below the belt, there is a company in the UK which makes underwear for both men and women with ostomy bags sewn in already. This is Vanilla Blush. Their range includes sexy panties and slips in a wide range of fabrics and colours. Check them out on the internet.

**Margaret Lindsay, NSW**

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Dear Editor,

I sympathise with Katherine Kingsbury in the August 2017 edition of our wonderful magazine re 'tight ' clothing around our waistlines!

Fortunately most men have the option of wearing the now ' fashionable ' braces. I like to wear trousers with a generous waistband, and with the aid of braces have never had a problem. My braces are worn underneath my shirt, but they could also be on the outside if desired. I have several pairs of braces, to avoid the necessity to having to keep changing from trousers to trousers!

David Gardiner, WA

Dear Editor,

Thank you to James Wallace for his suggestion of an overnight placement for urostomy bag. My son-in-law made me one and I find it very useful.

Maggie Parker, QLD

Dear Editor,

Some ostomates may be experiencing leakage around the stoma, resulting in raw and painful skin. If you are using a pouch with a pre-cut opening, then contemplate whether its configuration is appropriate for your little life-preserving creation.

Your preferred brand can supply a type that enables you to cut an aperture to suit your size and profile. You will need a special pair of curved scissors.

After my operation eight years ago, the stoma nurse at the Brisbane hospital where I had surgery introduced me to a cut-to-fit pouch and even supplied the scissors—which she told me to treasure as 'they are like gold around here'.

Eventually I moved on to the pre-cut variety, which have served me well until recently, when I experienced considerable leakage. I noticed a change in my stoma, and have reverted to the original cut-to-fit type. (I still have the scissors.)

When you enquire about free samples, ask if they can provide a pair. Make a couple of trial runs and then make a template for future use. Good luck.

John Geeves, QLD

Dear Editor,

I have an ileostomy and had been searching for a solution to my ballooning problem for many frustrating months. Leaks or the threat of one in the middle of the night had been so distressing. I'd tried every brand of pouch available here in Australia and none of the inbuilt filters had worked for me, even though they claim to 'minimize' ballooning!

My main ballooning problem was at night, in bed—it'd usually be 2am or 3am when I'd wake to find my pouch about to burst or, horror of horrors, leaking! So off I'd trot to the toilet to release the air from the opening end, but on returning to bed I was often so wide awake that I could not go back to sleep. And of course as we all know, lack of sleep does not make for a good day the next day.

Finally, wonderful indescribable relief! I found the answer on Facebook with a suggestion from someone in the Australian and New Zealand Ostomy Support Group. They said 'try a floating flange'.

Never having heard of an FF I rang around the stoma product supply companies but some of them did not understand what I was taking about. Then one company said 'Ah, an accordion flange'. They sent me samples and then I understood what an FF is! More phone calls and I found a few other stoma supply companies that also sent me samples. And that's when the magic happened!

A floating flange is the specially designed baseplate of a two-piece stoma pouch system. It allows fingers to be placed under the flange to help minimise pressure on the abdomen when attaching a pouch and is especially helpful for arthritic fingers like mine. I'd tried the two-piece system before but was unable to manage the connection between the base plate and the top pouch as I was also pressing down on soft and pliant tummy tissue.

I think the word 'accordion' better describes the shape and function of this baseplate. Also, floating flange is a name used by one company to describe all their baseplates, which is a confusing interpretation.

The top part, the specially designed pouch, has a small tab for a hernia belt each side of the underside opening and also another tab near the top which is used for lifting and reattaching it to the FF/accordion baseplate.

Now, if I wake and find myself about to float to the ceiling (and having taken the precaution of no food or drink after 7pm) I just reach down, eyes still closed, feel around for that little tab, gently and very carefully pull it open a smidgen, release the air and then close it. It closes with an audible snap that is very comforting. It's taken some getting used to and the trial of several brands of pouches and FF/accordion bases but these past few months I've managed six or seven hours of sleep each night—magic indeed!

Margaret Brabrook, QLD

Dear Editor,

Regarding Rod O'Sullivan's letter (April 2017) in which he asked about protective seatbelt products, I can suggest the 'Tummy Shield' (www.tummyshield.com.au/index.html). It is designed to re-route the lap portion of the seatbelt over the top of the thighs, rather than around the abdomen. It is intended for pregnant women, but I have successfully used one to keep the seatbelt away from my stoma.

Peter Nolan, ACT



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## Care centre is PNG's primary goal



Janet Yaki with, left, Heather James, president of Wide Bay Ostomates Association, and Trina McRae, Wide Bay's Appliance Officer. The Bundaberg-based association is one of those that supports the work of the PNG Stoma Association.

Establishing a permanent stoma care centre and a team of volunteers to operate it was the 'primary goal' of the Papua New Guinea Stoma Association, the group's founder and president, Janet Yaki, said in an address to the ACSA national conference in Melbourne in October.

The association had received a good deal of local support since 2014-15, when the PNG construction company Curtain Brothers had helped to ship supplies from Townsville. In 2015 Greg Neville of Matrix Constructions and the Neville family had donated an air-conditioned shipping container with installed shelving to store ostomy products, and had since donated a 12-seater bus. They had taken over the shipment of supplies from Australia, provided by Australian associations, and managed by Gold Coast Ostomy Association.

In other donations, Blaise Paru, with Alpha Insurance and the CPL Group of companies had provided two desktops and a laptop with an external hard drive. The Taiwan Overseas Medical Mission had

donated 25 flash drives, and the Gold Coast association had provided a new desktop computer and printer.

However, Janet said, "although PNGSA has received all this computer equipment through various donors, we still lack the office space to accommodate and utilise them."

The Nevilles had helped to provide architectural designs for the proposed stoma care centre building, which would provide the space to improve the association's operations, 'but PNGSA is still in need of land and finances to build the centre'.

'Despite numerous letters written and direct requests made by PNGSA, there has still not been any help from the state or the government health service providers,' Janet told the conference.

'I still continue to search for land through the Lands Department but to no avail, so I am still working from my home and the storage container. Because of this patients have access to my premises to collect

supplies, but fortunately my family have come to accept the minor inconvenience of a little less privacy for the benefit of those who are less fortunate.'

Despite these difficulties, Janet had continued her work in Port Moresby and the outer provinces and islands. On Wednesdays she goes to Port Moresby General Hospital's surgical clinic, working from a small cubicle provided by the hospital, to give ostomates supplies after they have been reviewed by doctors, and doing ward rounds to meet patients who have recently come out of surgery.

'This first contact is to introduce PNGSA to the new ostomates in order to address their need for supplies and also to give counselling,' Janet said. In all, she helps some 200 ostomates, with new ostomates being created each week.

Janet does not always know who will turn up at the Port Moresby clinic, even though she might have given them her number to call in advance. She usually takes a supply of bags for children and another for adults, to cover all possibilities. 'If I have what they want, I give it to them,' she says. 'If not, I can go to them.'

In the past year Janet has also extended her work outside the capital, because stoma care knowledge is 'not widespread', she says.

'I have travelled to Mount Hagen, located in the New Guinea Highlands region, and Buka and Rabaul, located in the New Guinea Islands region, to have stoma care sessions with the nurses from nine provincial hospitals, including Port Moresby General Hospital,' she said.

'The Highlands and Rabaul trips were sponsored by the Taiwanese Changhua Christian Hospital

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Overseas Medical Mission and the Buka trip was sponsored by Greg Neville.

'I pack supplies for patients for these hospitals who put in requests by the doctors, nurses or patients. I am getting requests from other provinces, such as Wewak, Vanimo and Oro, too, to which supplies are sent via services such as DHL. This is funded at my own expense, but when family or friends travel to those regions I use their assistance in delivering the supplies,' Janet said.

In another outreach venture, Janet plans to prepare a stoma care video which would show nurses in regional hospitals how to apply stoma products correctly, given that many nurses have not been trained in stoma care.

'Once I have the video completed and loaded on to the flash drives donated by the Taiwan Overseas Medical Mission, I will be able to distribute them to the 22 regional hospitals. This

will remove the need for me to travel to these hospitals to do demonstrations personally,' she said.

Janet told conference that she generally continued to work alone providing direct assistance and care. It had been difficult to get ostomates to volunteer their time to help with the logistics of receiving, sorting and delivering donated supplies—many were in poor health, in any case. Family and friends provided periodic support.

However, staff at QBE Insurance had given a strong response to an information session that Janet had delivered to a staff information session in August. People from that session had agreed to join Janet on her hospital visit at the end of October to get an understanding of the logistics and the ostomate care that PNGSA volunteers might provide.

Janet concluded with her thanks to Gold Coast Ostomy and

ACSA for their continuing support and generosity. Her organization had used both international and local support 'to slowly build a network that delivers supplies to ostomates in various regions of PNG where it is impossible to access such support'.

'PNGSA is committed to building on this initial foundational work by continuing to extend the network to more provinces of the country,' she said. 'PNGSA is still focused on working towards the building of the stoma care centre in order to centralize operations and support the current regional network that has been established.

'With continued awareness within the community it is hoped to also build a core group of volunteers to help administer these operations in the future.

'Despite the obstacles, all things happen in God's timing. He will deliver.'

## A continuing journey

*Like many another retiree, Frank Muggeridge set off to take a look at Australia – but things didn't go quite as planned ...*

In June 2014 my wife, Barb, and I sold up everything, bought a caravan and a new car and took off, supposedly for five years. I was then 79 years of age, in very good health, looking forward to travelling around Oz.

As a regular blood donor I was constantly looking for places to donate. Would you believe they are very sparse in our Outback? Darwin was booked out for some weeks. I was finally able to obtain an appointment at Port Adelaide, where I was rejected after an initial test because of low haemoglobin and a very high pulse rate. They advised me to see a doctor asap.

We were on our way to Victor Harbour to do a house sit for six weeks, so I booked in to the Victor Harbour Medical Clinic.

The GP I saw asked a few questions about our travels and my medical history (which was very good) and astounded me by saying that it was his opinion that I had bowel cancer. I needed to follow up with a gastroenterologist and then follow his directions.

This knocked me for six. Barb was waiting for me at the coffee shop across the road. She could tell something was wrong when I approached.

On reflection, the GP's questions reminded me of the few times I'd had cold shivers in the afternoon, and had been feeling drowsy and generally listless while we were travelling. I put it down to our

lifestyle and getting older.

These were some of the symptoms. If it hadn't been for the blood bank I probably would not have known.

After the gastro specialist I was sent to McLaren Vale hospital for a colonoscopy and endoscopy, then to Noarlunga Hospital for a CT scan, then to the colorectal clinic at Flinders Medical Centre. I was admitted within 10 days and had a golf ball sized tumour removed from my small bowel, along with 30cm of large bowel.

A number of times each day I was asked 'Have you passed wind?' On day five I nearly blew out a window—gee it felt good!

I had great support from our sons. One son, Dan, was with

Continued page 30

## Award recognises BCA's achievement

Bowel Cancer Australia's achievements in promoting health knowledge and awareness have been recognised by the award as NGO of the Year in the annual Prime health awards.

The awards are designed to reward excellence in healthcare communications and are supported by FarmaForce and the Clinical Research Corporation. Winners are selected by members of the Australian healthcare and pharmaceuticals industry.

Bowel Cancer Australia said the award highlighted the impact it was making, despite its comparatively small size and limited budget. It also recognised the collective effort of all who had helped BCA's work over the years.

BCA was founded in 2000 and has become the leading bowel cancer charity through initiatives such as Bowel Cancer Awareness Month and the BowelScreen Australia screening program. The organisation is wholly community funded.

The BCA's chief executive, Julien Wiggins, who accepted the award in Sydney on 14 September, believes the organisation's best work lies ahead as it focuses on creating change across the continuum of care.

## Ostomy clinic in Adelaide

Adelaide-based practice Colorectal Surgery has opened a specialised stomal therapy clinic for ostomates seeking pre- and post-operative counselling, education, support and assistance.

The service, staffed by stomal therapy nurse Amanda Summers and supported by the practice's team of surgeons, advocates annual reviews for ostomates.

'Our aim in providing this service is so ostomates can have access to regular reviews, thus preventing and treating early stomal complications before an ostomate's quality of life has deteriorated due to stomal problems,' the practice said in a statement.

The service is provided through Colorectal Surgery's head office at 142 Ward Street, North Adelaide. Appointments can be made by phoning (08) 8267 3355.

## Did you know?

3 out of 10 people with a stoma will develop a hernia.<sup>1</sup>

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us while I was having treatment. Because I was not allowed to drive, son Matt came to Adelaide and put me on the plane home, where son Rick collected me. Then Barb and Matt drove the van home.

Flinders hospital had asked me where I wanted to be followed up. I said the Mater Hospital in Brisbane would suit me nicely.

Within a few days of leaving Flinders hospital I had a phone call from the Mater and set up an appointment with their Cancer Care Centre for about 10 days' time.

On my visit to the Mater cancer care centre I was started on a six-month course of chemotherapy tablets. Fortunately I had no side effects.

But the Mater was not happy with a small spot that showed up near my right kidney, so a PT Scan was arranged. This proved positive to an unwanted cancer spot. I was then referred to Urology, and subsequently my right kidney was removed.

I spent recovery time in Ward 8B—for me, the best ward in the Mater.

On follow-up I had a CAT scan to check everything. Unfortunately, this time I reacted to the intravenous dye, and passed out. I was classed as a 'code blue', indicating the need for immediate emergency attention. I spent the next couple of days in the intensive care unit.

In March 2016 I had a bladder infection, which led to another stay in Ward 8B. A little later I had rigors, which resulted in another night in the ICU and a two-night visit to 8B. There was a viral bug in the system.

When Urology followed up, they discovered an aggressive cancer which resulted in the removal of bladder, prostate and urethral tube, and another stay in 8B—home away from home. This all happened in the 11 months from

October 2015 to September 2016.

I have been lucky not to have any other health problems, and there are no side effects.

This was my introduction to ileal conduit and stoma. What a lesson! Jenni, the STN, was a great person to have around. I was also introduced to the Gold Coast Ostomy Association—a great support group.

The biggest problem I have now is a 7cm prolapse. Urology checks me every six months to determine if there is a need for any further treatment.



Frank Muggeridge

I couldn't find a support garment for the stoma so, for comfort, Barb made some belts which proved successful.

Using baby nappy bags for disposal and commercial cleaning wipes cut into quarters for washing around the stoma and drying were wonderful suggestions. I change my bag (Barb has named it 'Gucci') every second day and the drainage bag weekly. When I am not wearing the stoma support belt, I use the small belt which attaches to the wafer.

When I attended Gold Coast Ostomy's informative, well-run and well attended seminar in April, I confirmed that, for my purposes,

the products I use are excellent. I also discovered a commercial support belt. I am now wearing a 17cm belt and have never felt more comfortable.

I've had the occasional leak in the wrong place at the most inconvenient time. This has been caused by my slackness, when I didn't smooth out the wafer properly. Luckily I carry a spare kit in the car.

One concern is the change in clothing needed. I can't wear a belt because it sits on top of the stoma, so I wear elastic-topped trousers and shorts. The problem is getting a high waist fit. To help with this I wear braces and a loose-fitting shirt or polo shirt. I would like to be able to have the waist lifted. I will soon visit a tailor for his recommendations.

To make matters easier to manage at home, we found on-line a small white cupboard with two shelves and two cane baskets at a discount department store. It fits between the toilet and shower—ideal for keeping the necessary supplies in zip-lock bags where they can be easily assembled. The vanity basin with mirror is ideal when changing the bag.

One thing I have done is to let family and friends know how it all works—there is no stigma attached. I couldn't believe the number of ostomates around Australia. It is a way of life, just like other disabilities. We are all in this together and should be prepared to help each other. I now attend an informative monthly get-together at Logan Hospital.

One principle I learned at a seminar in the early 80's was 'You can't argue with the scoreboard'. I have followed this principle ever since.

It simply means—forget what has happened. You can't change it. Focus on the future and live positively. ●

## National Directory of Ostomy Support Groups

### NEW SOUTH WALES

#### ALBURY/WODONGA BORDER DISTRICT

Meets: 10.00am on the second Tuesday of each month Feb to Dec.  
Venue: Hilltop Accommodation Centre, 600 Keene Street, East Albury NSW  
Contact: Alex Watson 0428 578 385

#### BATHURST

Meet on the first Tuesday of March, June, September & December at Daffodil Cottage  
Contact: Louise Linke (02) 6330 5676

#### BROKEN HILL

Meet: Every 3rd month or as required.  
Venue: Broken Hill Hospital Conference Room.  
Contact: Tandra (08) 8080 1333

#### CENTRAL COAST

Meet: 1.30pm to 3.30pm on the third Wednesday in Feb, May, Aug and Nov at a different venue each meeting.  
For further information, phone the Stomal Therapy Service on (02) 4320 3323

#### COFFS HARBOUR

Meets 2:00pm to 3:30pm  
2016 meeting dates to be advised.  
Venue: Sawtell RSL Club, First Avenue, Sawtell.  
Ostomates & friends welcome.  
Contact Mandy Hawkins STN on (02) 6656 7804

#### EUROBODALLA REGION

Meets first Sunday of Feb - Apr - Jun - Aug - Oct - Dec at 11am  
Venue: Laughter Room, Moruya Hospital.  
Phone: Betty (02) 4476 2746

#### FAR NORTH COAST

Meet at Lismore Workers Club  
225 - 231 Keen St. Lismore.  
11.30am - 2.00pm  
1st Saturday March, July, December.  
Contact: Marie: (02) 6686 7248

#### FAR SOUTH COAST

Bega & Surrounding Areas  
Meets second Sunday of Feb - Apr - Jun - Aug - Oct - Dec at 11.00am at a different venue each time. Flyers are sent to Ostomates 10 days beforehand.  
Inquiries:  
Eileen. Phone: (02) 6492 2530  
Geraldine. Phone: (02) 6492 2366

#### GRAFTON & DISTRICT

Meets first Thursday of each month from 9.00am to 11.30am  
Contact: Anne: (02) 6641 8200

#### GRIFFITH & DISTRICT

Griffith and the surrounding areas (100km radius including Leeton, Coleambally, Yenda, Hillston, Hanwood, Coleambally)  
Enquiries: Barry (02) 69635267 or 0429 635 267  
Email: ann.bar@bigpond.com  
Karan: 0434 785 309

#### HASTINGS MACLEAY

Meet: The Old Hospital at 10am to 12noon on the third Wednesday in

Feb - Apr - Jun - Aug - Oct - Dec.  
Inquiries: Neil 0427 856 630 or Glennie (02) 6583 7060

#### ILLAWARRA

Meets: 10.00am to 12 noon.  
2017: 26 April, 14 June, 30 October, 13 December (Christmas party)  
Jun - 17 Aug - 19 Oct - 14 Dec.  
Venue: Education Room, Figtree Private Hospital, 1 Suttor Place, Figtree 2525.  
For further information contact Helen Richards CNC STN (Wollongong Private Hospital) (02) 4286 1109 or Julia Kittscha CNC STN (Wollongong Hospital) 0414 421 021

#### MANNING/GREAT LAKES

Meet: 10.00 am to 12 noon on first Wednesday in Feb - Apr - Jun - Aug - Oct - Dec.  
Venue: Skills for Life Building, 5-9 Elizabeth Ave. Taree NSW (wheelchair accessible)  
Website: www.mglostomy.co.cc  
Contact: Karla MacTaggart on (02) 6592 9469

#### NEWCASTLE DISTRICT

Meet at 1.30pm on the last Saturday in Feb - May - Aug (AGM) - Nov.  
Venue: Hamilton Wesley Fellowship Hall, 150 Beaumont St. Hamilton.  
Enquiries: Geoff (02) 4981 1799 or Lynda 0425 209 030 or Maree (02) 4971 4351

#### ORANGE & DISTRICT

Meet: Mar - June - Sept - Dec From 12 noon.  
Venue: 15 Oliver St, Orange. NSW  
Contacts: Louise: (02) 6330 5676 and Joanne: (02) 6362 6184

#### SHOALHAVEN

Meet: 2.00pm. 2016 meeting dates to be advised.  
Venue: Nowra Community Health Centre, 5-7 Lawrence Ave, Nowra.  
Contact: Margaret or Tracey on (02) 4424 6300

#### SYDNEY - LIVERPOOL / CAMPBELLTOWN AREA

Meets: Thursdays from 1.00pm to 3.00pm in the Heritage Auditorium at Camden Hospital (Menangle Road, Camden).  
2016 meeting dates to be advised.  
For further information, please contact: Diane or Lu (STNs) on (02) 8738 4308

#### SYDNEY - PENRITH AREA

Nepean Educational Support Group will meet from 2.00-3.30pm on 28 April, 23 June, 25 August and 3 November 2017.  
Venue: Sydney Medical School, Clinical School Building, 62 Derby St., Kingswood.  
Family and friends welcome, afternoon tea supplied.  
Enquiries: Naomi Houston (stomal therapist) (02) 4734 1245

#### SYDNEY - NORTHERN AREA

Meet: First Wed. 10.00am - 11.30am monthly in the Jacaranda Lodge, Sydney Adventist Hospital,

185 Fox Valley Rd. Wahroonga.  
Contact: San Cancer Support Centre (02) 9487 9061

#### TWEED

Meets: third Tuesday of March, June, September and December from 12 to 2pm.  
Venue: South Tweed Sports Club.  
Contact: Jane Bright on 0409 671 162

#### WAGGA & DISTRICT

Meets: first Wednesday of each month from 10:00am to 11:00am.  
Venue: The Men's Shed, 11 Ashmont Ave, Wagga Wagga  
Enquiries: David (02) 6971 3346 or 0428 116 084  
Baz (02) 6922 4132

### VICTORIA

#### BAIRNSDALE & DISTRICT

Available for people to talk to and for home visits in the local area.  
Contacts: Janine: 0418 854 562  
Derelle: 0448 458 997  
Email: bdosg@hotmail.com

#### BALLARAT & DISTRICT OSTOMY SUPPORT GROUP

Meets: 2pm 2nd Wednesday of each month  
Venue: Barkly Restaurant, cnr Barkly St and Main Road.  
Contact: Graeme on 0400 979 742 or David Nestor on (03) 5339 4054  
Emails: david.nestor2@bigpond.com or graob44@gmail.com

#### BENALLA / WANGARATTA

Meets 2.00pm on the third Monday of each second month.  
Venues: Wangaratta Masonic Centre, 99 Appin St. Wangaratta in Apr - Aug - Dec and Benalla Masonic Centre, Cnr Benalla St. & Walker St, Benalla in Feb - Jun - Oct.  
Contact: Graeme Pitts, (03) 5762 1721 or 0407 240 943.  
Email: rexmar@bigpond.com

#### MILDURA

Meet: Every third month  
Venue: Mildura Base Hospital Conference Room  
Contact: Tandra (03) 5022 3333 or Norma 0409 252 545

#### SOUTH GIPPSLAND

Socials held on the first Tuesday of each month at 2:00 pm. Please contact Thea on 0447 942 406 for more information.

#### SUNRAYSIA / RIVERLAND

Venue: Sunraysia Cancer Centre  
Enquiries: Norma Murphy 0409 252 545

#### WARRNAMBOOL & DISTRICT

Meets at 10.30am on the second Friday of the month in Feb - Apr - Jun - Aug - Oct - Dec.  
Venue: The Seminar Room, SWHC Community Centre, Koroit Street, Warrnambool  
Contacts: Heather on (03) 5561 1159 or Terry on (03) 5562 5093  
Warrnambool Ostomy rooms (Fridays) (03) 5563 1446

### WESTERN AUSTRALIA

#### ALBANY

Meets at Albany Hospice conference room, 9.30am to 11am on the first Friday every three months.  
For details, contact Terry (08) 9847 4701 or 0428 502 530

#### PERTH (WAOA)

Venue: 15 Guildford Road, Mt Lawley.  
New members support orientation session: Second Saturday of every month, 12 noon-1pm.  
Weekend general support group: Second Saturday of every month, 1pm-3pm.

### QUEENSLAND

#### BEENLEIGH

Meets 10am - 12noon on last Monday of the month from Feb to Nov at Beenleigh Community Health Centre, 10 - 18 Mt. Warren Blvd. Mount Warren Park QLD.  
Contact: Logan Hospital Stomatherapy Unit, (07) 329 9107

#### BOWEN

Meets the first Wednesday of each month at Bowen Hospital, 10.30am.  
Contact: Natasha Leaver (07) 4786 8222 or Valerie McDonald 0407 691 160.

#### BRISBANE

Brisbane Ostomate Support Visitors Service (BOSVS) is a new ostomate visitor service operating in the Greater Brisbane Area.  
Phone: (07) 3359 6500.  
Website: qldstoma.asn.au/bosvs.htm  
Operating Hours: 7 days, 8am to 8pm.  
Operated by Qld Stoma Assn and Qld Ostomy Assn.

#### LOGAN

Meets 10am - 12noon on third Monday of each month at Logan Central Community Health Centre Corner Wembly & Ewing Roads  
Contact: Logan Hospital Stomatherapy Unit, (07) 3299 9107

#### MACKAY

Meets at 2.00 pm on the fourth Friday of every odd-numbered month (Jan - Mar - May - Jul - Sep - Nov).  
Venue: Meeting Room, Mackay Mater Hospital.  
Contact: Graham Stabler for further information on 0428 776 258 or email: grahamstabler@bigpond.com

#### REDCLIFFE

Meets first Tuesday each month at 10.00am in the Shillam Room, Redcliffe Cultural Centre - off car park Irene Street, Redcliffe.  
Enquiries: Dorothy Douglas (07) 5495 1335

## ROCKHAMPTON

Meet: 1.30pm third Saturday,  
Feb - May - Aug - Nov.  
Venue: Community Health Centre,  
Bolsover St. Rockhampton  
Contact: Frank & Marge Noy  
Phone: (07) 4921 0728

## SOUTH BURNETT

Meet second Tue. each month at 10am.  
Venue: Nanango Community Health  
Centre, Brisbane St. Nanango. QLD  
Contact: Anne Davoren  
Phone: (07) 4171 6750

## SUNSHINE COAST

Meets at the Small Meeting Room,  
Library Support Building, Cotton Tree,  
Maroochydore on the second Monday  
of every month from February 2016,  
commencing at 10am.  
Enquiries:

Winifred Preston (07) 5476 6313 or  
presto1849@hotmail.com  
Evon Fuller (07) 5447 7158 or  
eful@bigpond.com  
Laurie Grimwade (07) 54459008 or  
sid.and.laurie@gmail.com

## TOOWOOMBA

Insideout Toowoomba Stoma  
Support Group.  
Contact Margaret Brabrook,  
emby1936@gmail.com,  
(07) 4635 1697, or Leanne Wilshire,  
leanne.wilshire@bigpond.com  
or (07) 4630 0629

## WIDE BAY

Meets from 1.00pm to 3.00pm on the  
third Thursday each month at Wide  
Bay Ostomates, 88a Crofton Street,  
Bundaberg West.  
For information please contact  
Heather James: 0406 472 486 or  
leave a message on (07) 4152 4715

## TASMANIA

"SEMI COLONS" - a support  
group for men and women affected  
by colorectal cancer with or without  
ostomies. Meets in Hobart on the  
third Thursday of every month,  
from 2pm to 4pm.  
Enquiries: Cynthia Taafe, Senior  
Officer Support Services, Cancer  
Council Tasmania, on (03) 6169 1915

## NORTH & NORTH-WEST

**North:** Meets 10.00am on the second  
Wednesday of June, September and  
December at the Cancer Support  
Centre, 69 Howick Street, Launceston.  
**North-West:** Meets 10am on the  
second Wednesday of March, June,  
September and December  
at Ulverstone Senior Citizens Club,  
16 Edwards Street.  
Contact: Adrian Kok  
(03) 6326 4664

## SOUTHERN TASMANIA

A new group for southern Tasmania  
began on 8 March 2017 at Glenorchy  
RSL, 320 Main Road, Glenorchy.  
Meetings will be held on the first  
Wednesday of June, September and

December, from 10am till noon.  
Further information:  
Adrian Kok (03) 6326 4664

## SOUTH AUSTRALIA

### CENTRAL

Meet: Third Tuesday of Jan, March,  
May, July, Sept, Nov.  
When: 2pm.  
Where: Ileostomy Assoc Centre,  
73 Roebuck St, Mile End.  
Information: (08) 8234 2678

### FLEURIEU

2016 meeting dates to be advised.  
Meet: 10.00am until 12 noon at the  
Flinders Rural School, Bay Road,  
Victor Harbor.  
Please contact Sue McKay STN  
for further information on  
0412 692 418

### SOUTHERN

Meet: First Wednesday of Feb, April,  
June, Aug, Oct, Dec.  
When: 2pm.  
Where: Elizabeth House,  
112 Elizabeth Rd, Christie Downs.  
Information: Val: (08) 8381 1646

## NORTHERN TERRITORY

### DARWIN

Meet: 5.00-6.00pm on the first  
Tuesday of every month.  
Where: Cancer Council NT, 2/25  
Vanderlin Drive, Wanguri NT 0810  
Contact: Marg Lavery:  
(08) 8944 1800

### YOUTH GROUP

Doris Steyer,  
Telephone: (02) 4296 5354

### YOUNG OSTOMATES UNITED (YOU)

Tel: Helen (03) 9796 6623  
Web: www.youinc.org.au  
Email: helshae@hotmail.com  
Facebook:  
Young Ostomates United

### BOWEL GROUP FOR KIDS INC

Tel: (02) 4659 6067 or  
0431 857 188  
Email: enquiries@bgk.org.au  
Web: www.bgk.org.au

### PARENTERAL NUTRITION DOWN UNDER

Secretary on (02) 9987 1978  
Email: contactpndu@gmail.com  
Web:  
www.parenteral-nutrition-down-  
under.webs.com

### MITROFANOFF SUPPORT AUSTRALIA

PO Box 256, South Melbourne,  
Victoria 3205  
Email:  
info@mitrofanoffaustralia.org.au  
Web:  
www.MitrofanoffAustralia.org.au

## Stoma Appliance Scheme Product Suppliers



### AinsCorp

PO Box 572, Niddrie, Victoria 3042  
Toll Free Number: 1300 784 737  
Email: service@ainscorp.com.au  
Website: www.ainscorp.com.au



### Dansac

PO Box 375, Box Hill, Victoria 3128  
Phone: 1800 331 766  
Email: customerservice@dansac.com.au  
Website: www.dansac.com.au



### Coloplast

PO Box 240 Mt Waverley Vic 3149  
Freecall: 1800 653 317  
Email: au.care@coloplast.com  
Website: www.coloplast.com.au



### ConvaTec

PO Box 63, Mulgrave, Victoria 3170  
Freecall: 1800 335 276  
Email: connection.au@convatec.com  
Website: www.convatec.com.au



### Sutherland Medical

PO Box 1194, Huntingdale, Victoria 3166  
Phone: 1300 664 027  
Fax: 1300 664 028  
Website: www.sutherlandmedical.com.au



### Future Environmental Services

PO Box 319, Blairgowrie, Victoria 3942  
Phone: +61 3 5985 2828  
Email: health@futenv.com.au  
Website: www.futenv.com.au



### Hollister

PO Box 375, Box Hill, Victoria 3128  
Freecall: 1800 335 911  
Email: customerservice@hollister.com.au  
Website: www.hollister.com/anz/



### Nice Pak Products

Free call: 1800 506 750  
Email: healthcare@nicepak.com.au  
Web: www.nicepak.com.au



### Omnigon Pty Ltd

PO Box 5013, Burnley, Victoria 3132  
Freecall: 1800 819 274  
Email: info@omnigon.com.au  
Website: www.omnigon.com.au



### 3M Australia

Locked Bag 19, North Ryde NSW 1670  
Phone: 136 136  
Website: www.3m.com.au



### Statina Healthcare Australia

3/30 Leighton Place, Hornsby, NSW 2077  
Toll Free Number: 1300 365 404  
Email: sales@statina.com.au  
Website: www.statina.com.au